Meeting Summary
Advisory Panel on Medicare Education (APME)
Wednesday, January 10, 2001
***Medicare Education Budget and Priorities: 2000-2001 & 2001-2002,* and**
Providing Culturally and Linguistically Appropriate Information
To Medicare Consumers – An Examination of Model Programs

Location:

The meeting was held at the Madison Hotel, 1177 Fifteenth Street, N.W., Washington, D.C., 20005.

Federal Register Announcement:

The meeting was announced in the *Federal Register* on December 21, 2000 (Volume 65, Number 246, Pages 80443--80444) (Attachment A).

Panel Members Present:

Diane Archer, President, Medicare Rights Center
David Baldridge, Executive Director, National Indian Council on Aging
Bruce Bradley, Director, Managed Care Plans, General Motors Corporation
Carol Cronin, Chairperson
Jennie Chin Hansen, Executive Director, On Lok Senior Services
Joyce Dubow, Senior Policy Advisor, Public Policy Institute, AARP
Bonita Kallestad, Western Minnesota Legal Services/Mid Minnesota Legal Assistance
Steven Larsen, Maryland Insurance Commissioner, Maryland Insurance Administration
Brian Lindberg, Executive Director, Consumer Coalition for Quality Health Care
Heidi Margulis, Vice President for Government Affairs, Humana, Inc**.**
Dr. Patricia Neuman, Director, Medicare Policy Project, Kaiser Family Foundation
Samuel J. Simmons, President and Chief Executive Officer, National Caucus and Center on Black Aged
Nina M. Weinberg, President, National Health Council
Edward Zesk, Executive Director, Aging 2000

Staff:

Nancy Caliman, Center for Beneficiary Services, Health Care Financing Administration (HCFA)

Others:

A sign-in sheet listing other attendees is incorporated as Attachment B.

Absent:

Dr. Elmer Huerta, Director, Cancer Risk and Assessment Center, Washington Hospital Center
Dr. Elena Rios, President, National Hispanic Medical Association

Welcome and Opening

Nancy Caliman, Center for Beneficiary Services, Health Care Financing Administration, called the meeting to order at 8:10 a.m. She stated that there would be an opportunity for public comment near the conclusion of the meeting. Those wishing to make a public comment needed to sign up on a special list.

Carol Cronin, Chairperson of the Advisory Panel on Medicare Education (APME), welcomed the group and reviewed the agenda and speakers.

Recap of Previous Meeting
Carol Cronin, Chairperson

Ms. Cronin summarized the previous APME meeting that was held September 21, 2000 in Oakland, California. The meeting focused on providing Medicare information to consumers with limited English proficiency (LEP). She said that the presentations and discussion gave APME members a grassroots perspective of what people with LEP face in trying to understand the complicated Medicare program. Members engaged a community-based panel on their reaction to a video in which caregivers and beneficiaries described their efforts to obtain health care and Medicare information. The discussion framed the issues in a set of themes. The main themes included: the importance of community partnership building and the ability of HCFA to work closely with community-based organizations; the role of the State Health Insurance Assistance Programs (SHIPs) in working directly with people who have LEP; the importance of training, translation and interpreter services; giving more attention to adult children and caregivers; and, appropriate funding to support these efforts. The day following the meeting, Jennie Chin Hansen hosted APME members on a site visit to On Lok Senior Services in San Francisco. The visit gave them a hands-on perspective of how a community-based organization provides services to a distinctive population.

Introduction of APME Members

Carol Cronin led the introduction of panel members.

HCFA Update/Issues
Robert A. Berenson, M.D.
Acting Deputy Administrator, HCFA

Dr. Berenson thanked panel members for their commitment to serve and for their support for adequate Medicare education particularly for those beneficiaries with limited English proficiency. He began his update by discussing the recently enacted Medicare, Medicaid, State Children's Health Insurance Program Benefits Improvement and Protection Act of

2000 (BIPA). The Act provides increased payment levels to Medicare + Choice organizations. The Congress intended that the increased payments would curtail the non-renewal of Medicare +Choice (M +Choice) contracts and stabilize the program. Congress hopes that some plans will re-enter the program to lessen the negative impact on seniors who lost their Medicare HMOs. The Act also slowed but affirmed the need for risk adjustment of payments to plans. Dr. Berenson described HCFA initiatives to make the agency a better business partner for Medicare +Choice organizations. These initiatives include: reorganization of the Center for Health Plans and Providers to improve coordination with M +Choice organizations; development of a comprehensive manual of M +Choice requirements; and, initiation of a contract to analyze the burden on M +Choice organizations of participating in the program.

Dr. Berenson next discussed the outcome of the Grijalva v. Shalala Settlement Agreement. The Agreement calls for enhanced rights for enrollees in Medicare +Choice plans to appeal the termination and proposed termination of health services. HCFA will publish for public comment a proposed regulation to address the notice and appeals procedures. The final rules will be announced by December 31, 2002.

Dr. Berenson also discussed the 2002 Quality Assessment and Performance Improvement projects that Medicare +Choice organizations must undertake. In 2002, the plans must undertake projects to either reduce clinical health care disparities or provide culturally and linguistically appropriate services. The clinical disparities projects may focus on diabetes, pneumonia, heart failure or mammography. The culturally and linguistically appropriate services may be in such areas as interpretation services, outreach to affected communities or identification of providers with special experience or expertise. HCFA is also looking at best practices so that plans can serve as national models in providing culturally competent health care.

Finally, Dr. Berenson discussed a recent article in the *New York Times* that erroneously stated that HCFA was changing its instructions to Peer Review Organizations (PROs). The article said that HCFA would order PROs to release information to Medicare consumers about health providers who commit medical errors. Dr. Berenson said that existing laws and regulations require PROs to provide beneficiaries with the final disposition of their complaints as long as the information does not explicitly or implicitly identify an individual physician or other health care practitioner without their consent. However, HCFA is considering proposing changes to the existing rules. The agency will seek the public's comments on permitting disclosure of PRO information about physicians and other individual practitioners without their permission in order to inform beneficiaries and to provide them with more information about their complaints.

Responses from APME Members

Following Dr. Berenson's remarks, APME members, as individuals, made the following observations:

1. Consumers need clarification regarding the PROs' responsibility in the event that they uncover grievous medical errors.
2. HCFA can do more to promote health plans' best practices.
3. Although the relationship between HCFA and Medicare +Choice organizations has improved, the program is still in serious trouble. The Medicare +Choice program must be changed in the context of fee-for-service modernization and transforming Medicare into a program based on informed consumer choice. The payment methodology must be fundamentally changed.
4. HCFA should investigate the Medicare consumer coalition concept as a way to stabilize the Medicare + Choice program. HCFA's credibility with consumers, as well as that of Medicare +Choice organizations, has been impacted by health plan non-renewals.
5. The Center for Beneficiary Services (CBS) should play an important role with the new managed care office within the Center for Health Plans and Providers.
6. There is an inconsistency between Congressional discussion on reducing Medicare expenditures while the Congress increases payments to Medicare +Choice organizations.

Legislative Update
Peter Hickman, Director, Part B Analysis Group
Office of Legislation, HCFA

Mr. Hickman described the major provisions of the Medicare, Medicaid, and State Children's Health Insurance Program Benefits Improvement and Protections Act of 2000 (BIPA) (Attachment C). He said the BIPA will increase federal spending by $15 billion with the highest percentages going to hospitals and managed care plans. Some of the benefits improvements include:

- Reduction in the periodicity for Pap smears for other than high-risk beneficiaries to two years from three years.
- Glaucoma screening for high-risk individuals. This was formerly a benefit for symptomatic persons only.
- A new medical nutrition therapy benefit for beneficiaries with kidney disease who are not at the end-stage of kidney disease.
- Reducing the effective beneficiary co-payment for outpatient hospital services.
- Removing the time limit and cap on coverage for immunosuppressive drugs.
- Waiver of the 24-month waiting period for disabled entitlement to Medicare for persons with Lou Gehrig's disease (amytrophic lateral sclerosis -- ALS).
- A delay in the cap on therapy services for one additional year.
- Reducing the statutory useful life of a prosthetic device from five to two years, and allowing beneficiaries to obtain new prostheses after two years if their doctors approve the need.

Other provisions include:

- Requiring the Department of Health and Human Services to fund nine demonstrations to address reducing racial and ethnic disparities in the detection and treatment of cancer and to ensure cultural competency and language access. The demonstrations are to be focused on each of the following populations: American Indians, Asians and Pacific Islanders, African Americans and Hispanics. $25 million is set aside for these projects in the 50 states and additional monies will be provided for those in the territories.
- Requiring Medicare +Choice programs to focus on ethnic and racial minorities in their quality improvement programs.
- Modification of appeal rights for beneficiaries in fee-for-service disputes.
- Allowing beneficiaries to appeal national and local coverage decisions. The Departmental Appeals Board will hear appeals of national coverage decisions and Administrative Law Judges will hear appeals of local coverage decisions.

Medicare + Choice provisions include:

- Increasing the minimum payment amounts to Medicare +Choice (M +Choice) plans.
    - HCFA provided the new rates for M +Choice plans on January 4 and the plans had until January 18 to inform HCFA if they wanted to re-enter the program.
    - For continuing M +Choice plans, the increased payments will have to be used for benefits and cost sharing improvements, deposits and benefits stabilization funds or for network stabilization or enhancement.
- Lengthening the phase-in period for risk-adjusted payments to M +Choice plans.
- A change in the payment methodology for End State Renal Disease (ESRD) beneficiaries in M +Choice plans.
- Allowing beneficiaries with End Stage Renal Disease in non-renewing M+Choice plans to enroll in another M +Choice plan. This is retroactive to January 1999.
- A risk-adjusted payment for beneficiaries with congestive heart failure in plans that are the sole coordinated care plan in an area.
- A 5% bonus for plans in counties that would otherwise be abandoned as of January 1, 2001.
- Improvement in Medigap rights for beneficiaries in non-renewing plans and in cases of voluntary disenrollment.
- Allowing M +Choice beneficiaries in need of post-hospital skilled nursing facility (SNF) services to have an election to return to their previous SNF, the one in their retirement community or the one in which their spouse resides.
- Expediting the approval of M +Choice marketing materials that use model language.
- Enrollments in M +Choice plans in one month are effective the first of the following month.
- An increase in civil money penalties for terminating M +Choice contracts before the end of the contract term.

- Requiring the Secretary of Health and Human Services to develop a simplified national application for the Qualified Medicare Beneficiary (QMB) and Specified Low-Income Medicare Beneficiary (SLMB) benefits.
- A requirement that the Social Security Administration do outreach to identify and notify potential QMB/SLMB eligible persons and supply a list of their names and addresses to states.

HCFA Budget Process
Lee Mosedale, Deputy Director
Office of Financial Management, HCFA

Mr. Mosedale described the process HCFA undertakes to develop its budget (Attachment D). He said that, at any point in time, HCFA is dealing with three budgets -- the current year, the budget year and the budget year plus one. Using the example of the 2002/2003 budget, he explained the process and time frames.

HCFA's Financial Management Investment Board (FMIB), Executive Council (EC) and Office of Financial Management (OFM) have roles within the agency in budget development. The FMIB represents all the centers and offices in the agency. The OFM and the FMIB request guidance from the EC on their needs for the 2003 budget.

This target request goes to the Secretary of Health and Human Services in June. The Department's Budget Review Board discusses and approves the budget requests. After this review, the budget is sent to the Office of Management and Budget (OMB) by September. There are appeals procedures, if the Secretary disagrees with the OMB decisions. After the OMB process is complete, the agency develops a public document on the budget called a "green book". This document goes to the Congress by February.

House and Senate Appropriations committees may hold hearings on the budget in the spring of the year. The target dates for approval are before the end of the fiscal year in September 30 of each year although, as in 2000, the Congress may not meet that goal.

Mr. Mosedale described some of the pressures on HCFA's budget:

- The Medicare budget is difficult to market to Congress because of its size. Currently the budget is $370 billion. Of that amount, $240 billion is for Medicare and $120 billion is for Medicaid including the State Children's Health Insurance Program. It is difficult for Congress to agree when the agency requests additional discretionary funds to administer the program.
- Administrative costs associated with the program are less than three percent. Program management supports the operation of various programs and initiatives including: survey and certification functions, payments to state Medicaid agencies, payments to the Social Security Administration for establishing eligibility, carrier and intermediary (Medicare contractor) payments, fighting health care fraud and abuse, research programs, and payroll costs.

- Congress cut user fees, which funded the Medicare education program, severely last year. HCFA requested a $150 million education program to be funded entirely by user fees. Congress approved a $100 million education program with only $17 million to come from user fees, via a formula fixed in law, with the remainder coming from appropriations.
- When the budget passes before other legislation that impacts HCFA, such as the Benefits Improvement and Protection Act of 2000, the agency does not have the opportunity to factor in the administrative costs attendant with the legislation. That situation creates a burden on the agency.
- Industry events also have an impact on the budget. When Medicare +Choice organizations pull out of markets, the agency has to pay claims and for medical review for beneficiaries who are now in the fee-for-service side of the program. Nursing home and home health agency bankruptcies may leave the agency with uncollected overpayments.
- This year, Congress set aside a large amount of money for research for specific institutions making it very difficult for the agency to conduct an independent research program.
- Contractors complain when the Medicare operations budget goes for costs other than for contractors and they do not benefit from the increases. Systems costs, such as for managed care system redesign, must be developed and maintained out of the operations budget. These costs consume the operations budget.
- The General Accounting Office and Congress have pressured HCFA to make costly improvements in its accounting operations.

Mr. Mosedale explained that some funds for Medicare education come through the budget for the Peer Review Organizations. PRO funding does not go through the appropriations process. The funding comes directly from the Medicare trust fund and is controlled by the Office of Management and Budget (OMB) in three-year cycles. This year, HCFA must submit its education budget through the Congressional appropriations process and it must submit the PRO budget to the OMB. Congress authorized funding for the Medicare Integrity Program as a permanent appropriation and the appropriations committees have no control over the levels.

An APME member asked Mr. Mosedale how the committee could influence the funding of Medicare education. Mr. Modesdale said that the committee could recommend a certain level to Ms. McMullan, however the appropriations committees will have a great impact on the final numbers. He said the budget "green book" would contain the detailed budget submission. If the committee wants to have a voice in the 2002 budget, it must do so by the spring.

Medicare Education Budget and Priorities 2000-2001 and 2001-2002
Michael McMullan
Acting Director, Center for Beneficiary Services, HCFA

Ms. McMullan discussed Medicare education budget allocations for the 2000-2001 and 2001-2002 fiscal years. In fiscal year 2001, HCFA has a Medicare education budget of

approximately $102 million. That includes program management funds, user fees and the Peer Review Organization (PRO) budget.

- This fiscal year, HCFA spent approximately $26 million to develop, print and mail the *Medicare & You* handbook. Next year, handbook costs will be approximately $30 million.
- This year, HCFA is spending approximately $35 million to manage the Medicare Helpline (1(800) MEDICARE). The projected cost for next fiscal year is $40 million.
- This year, HCFA is spending approximately $7 million on the award-winning Medicare.gov website. Next fiscal year, it plans to spend $5 million on the website.
- Next year, HCFA will spend about $16 million on the State Health Insurance Assistance Programs (SHIP), about the same as in past years, and $15 million for the Consumer Assessment of Health Plans (CAHPS) survey.

In response to a member's question, Ms. McMullan said that the education budget ($102 million) and the research budget ($139 million) are not related. The research that impacts the education budget focuses on consumer testing of consumer publications.

Ms. McMullan discussed State Health Insurance Assistance Program (SHIP) funding. She said the number of beneficiaries who use the SHIP has not grown substantially in recent years despite the growth in funding (from $5 million to $16 million annually over the life of the program).

Ms. McMullan responded to a question on contractor budgets and priorities for education. She said the contractor budget for beneficiary education is the same this fiscal year as in the previous year. Their contractor education priorities are responding to telephone, written and walk-in inquiries, and customer service or outreach plans.

A member suggested that HCFA and the APME give attention to strengthening the SHIP program given the complexity of the Medicare program and the limitations in explaining its complexities in publications. This problem is particularly acute for LEP and low-literate beneficiaries. Ms. McMullan said that one-on-one counseling is not possible in a program of 40 million beneficiaries. She also described the 1(800) MEDICARE call volume – 3.7 million last year with an average length of 6 minutes. Another member commented that many SHIP volunteers became overwhelmed with the complexities of Medicare and consequently left the program.

Ms. McMullan said that most persons who visit the Medicare.gov site access the comparison information on nursing homes, health plans and Medigap. The questions asked via the toll-free Helpline depend on the time of year. During open enrollment time, most questions are about the availability of Medicare +Choice plans and Medigap policies. During the rest of the year, calls focus on Medicare + Choice and publications. Ms. McMullan explained that calls to the Helpline are handled in the following manner: by an automated attendant if the caller, for example, wants a publication; by a customer

service representative for routine questions; and, by the reference center for more complex questions. Helpline staff refer state-based questions to the SHIPs.

One member spoke to the limitations of the SHIP program. She said: some SHIPs are handling as many calls as they can; it is very difficult to train and retain volunteers; and, even after thorough counseling, beneficiaries may not act on the information they receive for a variety of reasons. Ms. McMullan said that HCFA would modify its train-the-trainer program to reach more people and to be available the year around.

Executive Session – Closed to the Public

Linguistic and Cultural Competence Standards and Research Agenda
Guadalupe Pacheco, Special Assistant to the Director
Office of Minority Health, Department of Health and Human Services

All members attended a training session that was closed to the public. Mr. Guadalupe Pacheco, Special Assistant to the Director, Office of Minority Health, Department of Health and Human Services (DHHS), conducted the session. He described the DHHS linguistic and cultural competence standards and research agenda.

Resumption of Public Session

Panel Discussion: Providing Culturally and Linguistically Appropriate Education and Information Services to the Medicare Population: An Examination of Model Programs

Ms. Cronin stated that the panel discussion would follow the format that was used successfully during the September 21, 2000 APME meeting in Oakland, California. She introduced the four panelists: Dr. Lauren LeRoy, President of Grantmakers in Health; Ms. Mimi Chafin, Grants Coordinator, Office of Minority Health, Department of Health and Human Services; Ms. Linda Okahara, Community Services Director, Asian Health Services, Oakland, California; and, Ms. Lela Keys, Delta Community Partners in Care, Clarksdale, Mississippi.

The Role of Foundations vs. the Role of Government
Dr. Lauren LeRoy, President and CEO
Grantmakers in Health

Dr. LeRoy provided the APME panel with her insight into the role of government and foundations in providing culturally and linguistically appropriate information and education services for Medicare beneficiaries. She stated that since taking the leadership of Grantmakers in Health, she has tried to foster stronger working relationships between philanthropy and government including encouraging foundations to support Medicare beneficiaries as they tried to understand Medicare and make informed health choices. Grantmakers also has a series of activities related to racial and ethnic disparities in health and cultural competence.

Dr. LeRoy said that while government and philanthropy have similar interests, they are unclear about how to relate to each other. However, the effort to understand the other is worth the effort when collaboration is successful. She noted that, in recent years, the lines of responsibility for public policy have blurred between the government and private sectors. She said that the public sector, including HCFA, has an increased interest in leveraging partnerships. Philanthropic institutions, on the other hand, are looking to government to leverage their funds. However, the mentality of "who pays" is not an effective partnership strategy. The best measure of success is in the impact of working together.

Dr. LeRoy said that building lasting relationships requires a sustained effort and an awareness of the constraints and advantages of each sector. She discussed the assumption that philanthropy is free of the legal and bureaucratic constraints of government and thus can be innovative and risk-taking. She said that foundations also operate within legal and organizational constraints and that many boards are uncomfortable with taking risks.

Dr. LeRoy stated her admiration for what HCFA has accomplished in educating beneficiaries and connecting with organizations that can further this cause. She said that it is unrealistic to expect HCFA or any national agency to tailor its information to meet the specific needs of different populations groups in communities across the country. Dr. LeRoy said that HCFA could support community information needs by providing resources and training, and by building national networks. Foundations can have a role by assessing community information needs, identifying organizations serving different population needs, funding outreach, guiding beneficiaries to make health choices, conducting research and providing community-based services.

Dr. LeRoy described Medicare education efforts by national and large state foundations including the Kaiser Family Foundation, the California HealthCare Foundation and the Robert Wood Johnson Foundation. She said that local foundations could fund the adaptation of Medicare materials for local use. However, few local foundations have taken an interest in doing this. She said that there is work to be done to convince foundations to focus on aging and health and to convince foundations that concentrate on linguistically and culturally appropriate services to target the elderly population. She described the types of services foundations are funding. These services include: focus group research, Internet-based health insurance counseling, education and outreach to limited English proficient populations, translation and interpreter services, immigrant health, recruiting bilingual health staff, community support groups, community health advocacy, and companion services to medical appointments.

Dr. LeRoy concluded by stating that foundations could play important roles as conveners and intermediaries by bringing HCFA and its regional offices together with various community groups including churches, cultural groups, health organizations and the media. She encouraged the APME to use its influence by articulating where actions by non-governmental organizations could further HCFA’s educational goals. This influence could help shape philanthropic institutions’ agendas for the future.

Mimi Chafin, Grants Coordinator, Health Grant Programs
Office of Minority Health, Department of Health and Human Services

Ms. Chafin stated that the Office of Minority Health (OMH) was established in law in 1991 under the Disadvantaged Minority Health Improvement Act. The legislation stated that the OMH was to support activities to assist health care providers in servicing their bilingual populations. Initially, OMH awarded cooperative agreements to national minority organizations. In 1993, it began the Bilingual/Bicultural Service Demonstration Program. Since that time, OMH has funded six competitive cycles awarding 100 grants totaling almost $9 million. In 1995, OMH decided to fund projects for three years instead of one year and to increase the funding from $75,000 per year per grantee to $100,000 per year per grantee. The office encouraged grantees to partner with health facilities to assure a continuum of health services for the population.

In 1997, the OMH decided to fund a set of grants focusing on managed care education. At the same time, they required grantees to document their relationships with health facilities. The 1998 cycle was similar to the 1995 cycle with the added requirement to document partnerships. In 2000, OMH funded 11 grants through the program and placed an emphasis on rural areas. They are currently planning the 2001 program and will publish an announcement in the Federal Register in a few months. They expect to have $2.5 million in funds available.

Ms. Chafin provided the members with a packet that included a fact sheet on the 1997 managed care program, a list of project officers for the various fiscal year programs, and a list of other programs offered by the OMH (Attachment E). She said that the Office had conducted an evaluation of the 1993 and 1994 projects and found that the projects were successful in meeting their objectives of improving communication and increasing access. There were, however, barriers that grantees faced including recruiting and retaining staff, and the evaluators suggested increased technical assistance from OMH.

Ms. Chafin said that OMH wants to disseminate the information they have gathered from the program including models for service delivery and materials developed under the grant. They are also encouraging grantees to identify funding to continue their programs beyond OMH funding. Some have absorbed the programs into their budgets, some are seeking philanthropic funding, and some are offering provider training for a fee.

Grantee Perspectives
Linda Okahara, Community Services Director
Asian Health Services, Oakland, California

Ms. Okahara said that Asian Health Services (AHS) serves a population that speaks Chinese, both Cantonese and Mandarin, Vietnamese, Korean, Cambodian, Mien, and Lao (Attachment F). They provide services, telephone contact, and education in these languages. Fourteen percent of their patients are dually eligible for Medicare and Medicaid and a small percentage have Medicare only. AHS has a budget of $10.5 million and a staff of 135, 80% of whom are bilingual. The mission is to serve and advocate for

the Asian community by ensuring access to health care services regardless of income, insurance status, immigration status, language or culture. AHS services and programs include: primary medical care, health education and outreach, expanding access to care for uninsured persons, language and cultural access, advocating for contract regulations pertaining to cultural and linguistic standards for Medicaid managed care organizations, health care interpretation and translation services, medical interpretation training, written translation and cultural adaptation of health materials, and conference interpretation equipment. Areas in which they target health education include teen pregnancy, HIV/AIDS prevention, diabetes control, breast and cervical cancer prevention, managed care education, and flu immunization. The value statement of Asian Health Services is *"Measure success not only by number of patients served, but also how fully our community understands and asserts its rights to quality health care."*

Ms. Okahara discussed the AHS funding sources, which include federal and local government, and foundations. Some of their funders are the Centers for Disease Control and Prevention, the Office of Minority Health, and the Robert Wood Johnson, Kaiser and Kellogg Foundations. AHS has been successful in obtaining funds from a variety of sources in part, because of their strategic planning. Their planning leads them to pilot strategies and obtain funding for programs employing the strategies after they have demonstrated their commitment. She noted that some foundations are encouraging non-profit organizations to engage in social entrepreneurship and the development of self-sustaining services. AHS has reached 50% self-sufficiency on some services. In the future, the fees obtained from these services may help the organization fund advocacy efforts that they cannot fund through government sources. She further said that AHS has had difficulty obtaining funds to do one-on-one counseling.

Lela Keys, Project Director
Delta Community Partners in Care
Clarksdale, Mississippi

Ms. Keys described the *Delta Community Partners in Care* project (Attachment G). It serves the Mississippi Delta, a predominantly rural isolated area in northern Mississippi. Hypertension and diabetes are two dominant chronic disease disorders in the Delta that place a significant burden on the population. These disorders involve lifelong drug therapies and lifestyle modifications that are difficult to achieve in a population that experiences multiple barriers to health care. One of the major barriers affecting the health of the population is illiteracy. Other barriers are inadequate transportation, lack of insurance, and lack of continuity in care.

Delta Community Partners in Care was developed by the Northwest Mississippi Regional Medical Center in concern for the many patients, ages 30 to 45, coming in with stroke, and undiagnosed diabetes. The Medical Center, in cooperation with local providers, community members and health consumers, planned a project to case manage hypertensive and diabetic individuals and educate the community to take care of its health care. They obtained initial funding from the Kellogg Foundation and expansion funding from the Health Resources and Services Administration (HRSA).

Delta Community Partners in Care provides community-based case management and health education and screening. The case management encompasses coordination of patient visits, in-home visits, medication assistance, disease specific health education, community education and support groups, health promotion and screening, follow up monitoring and evaluation, and advocacy. Community education is available to the general population but the majority who participate are Medicare beneficiaries.

Ms. Keys said that the *Partners in Care* program has been successful according to several indicators. These indicators include successful weight loss, increased physical activity, reduction in salt, fat and sugar intake, smoking cessation, reduced emergency room and inpatient utilization, increased disease knowledge, improved blood pressure and blood sugar control, and improvements in health status.

Ms. Keys described continuing barriers to health care. These include lack of transportation, insufficient in-home assistance for elderly and disabled consumers, the need for medication assistance, reading materials that are too technical or in small type, and the need for community resource centers to assist consumers with understanding health information. Ms. Keys said that her experience with Medicare beneficiaries is that they do not understand the program. She said they do not understand what Medicare covers or how to use the benefits appropriately. She believes that consumers would be empowered by a sense of ownership of their Medicare benefits.

Ms. Keys said that the community has many unmet health care needs. They need funding for health education centers and technology to develop materials that will engage the community using pictures and simple language. They also need technical assistance, training and cost analysis to show the cost effectiveness of their program. This would encourage others to replicate or fund the program. Ms. Keys said there is also a need for funding to expand their services to focus on other diseases common to the community especially cancer and asthma. She also suggested reimbursement consideration for providers, hospitals, primary care providers and others who serve a disproportionate share of high risk chronically ill patients, and reimbursement consideration for case management, education and prevention services. She said that because there is only 1% managed care penetration in the state, providers are bearing the burden of caring for the chronically ill, at-risk population. She also noted that there is very little health education available besides that provided by *Delta Community Partners in Care*.

APME Members' Discussion with Panel

APME members engaged the panel in a question and answer and discussion session. The panelists and APME members made the following points during this period:

The Importance of Data

Dr. LeRoy stated that philanthropic organizations are increasingly expecting grantees to provide data documenting the results of their projects.

Locating Community-Based Health Projects or Organizations

- Grantmakers in Health is developing a database of health-related projects that foundations are funding.
- The Office of Minority Health has a database of the groups it has funded. It is also helping a set of community-based organizations build their infrastructure to enable them to obtain grants for HIV/AIDS funding.
- The Health Resources and Services Administration (HRSA) has compiled a best practices database among grass roots organizations.
- Grantmakers in Health and HRSA have entered an agreement to develop compatible databases of projects and grantees that both entities are funding. This will facilitate linking with community-based organizations.
- The Public Health Service and the Community Health Centers Program may be a good sources to collaborate with foundations in terms of leveraging private and public funding for community-based health projects.

Reaching Consumers with Low Literacy Levels

Ms. Keys said that *Delta Community Partners in Care* uses a variety of methods to reach people in the community who have low literacy. They use simplified materials and videos. They are also willing to go out to non-traditional community locations such as grocery stores, parks and churches.

Discussion Among Panel Members

Ms. Cronin stated that the discussion would focus on two areas: 1) making specific recommendations on providing culturally and linguistically appropriate education and providing services to those with limited English proficiency and 2) planning for the coming year.

One panelist said that HCFA should consider collaborating with the National Indian Health Board, the Indian Health Service, the American Diabetes Association and the Centers for Disease Control to provide diabetes information to Indian elders. Ms. McMullan said that HCFA's Office of Clinical Standards and Quality is doing a great deal of work on diabetes and that the panel could receive a briefing on those efforts.

One panelist asked Ms. McMullan about HCFA's process for determining how to target materials to specific communities with special needs. She said that HCFA works with agencies within the Department of Health and Human Services that have primary clinical responsibility. For example, the agency with which HCFA collaborates on diabetes is the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). HCFA takes the NIDDK basic materials and targets them to the Medicare population. The Peer Review Organizations develop materials primarily targeted to providers but they also do wraparound materials for patients. In the instance of basic Medicare materials, HCFA prepares all consumer publications in English and Spanish and prepares some in Chinese. Some HCFA Regional Offices translate certain Medicare materials into other languages

based on their populations. For example, the Boston Regional Office translates some materials into French and the Seattle Regional Office translates some materials into Asian languages.

The APME members discussed strategies for developing a recommendation for appropriate funding for Medicare education. After discussion, the panel asked that HCFA, either through its staff or a consultant, prepare a background paper on Medicare education that would include:

1. The nature of the problem and the importance of helping Medicare beneficiaries make more informed health decisions.
2. An analysis of what has been done by HCFA and others to try to address the problem.
3. A discussion of the gap between what has been done and what needs to be done.
4. Some analysis of the level of funding necessary to close the gap.

The APME members agreed that discussion on the background paper would be on the agenda for the April 26, 2001 meeting. Some members suggested that the paper take into account the information needs of limited English proficient beneficiaries and the desirability of HCFA working with community-based organizations.

Ms. Cronin asked members about their preference for having another meeting outside of Washington, D.C. Some members said they would be willing to travel to another location if there were some experience or perspective to be gained that would inform their thinking.

Public Comment

No member of the public signed up or indicated orally that they wished to make a public statement at the meeting.

Next Meeting

The next APME meeting would be held on Thursday, April 26, 2001 in Washington, D.C.

Adjournment

The Chair adjourned the meeting at 4:36 p.m.

Prepared by:
Nancy M. Caliman, Health Insurance Specialist
Partnership Development Group/Center for Beneficiary Services
Health Care Financing Administration

Approved by:
Carol Cronin, Chairperson
Advisory Panel on Medicare Education